

‘If I were given the chance’: understanding the use of leisure time by adults with learning disabilities.

Abstract

Despite UK government policy emphasising the rights and choices of people with learning disabilities, opportunities to choose fulfilling leisure activities remain severely constrained. Following a brief literature review we present a co-inquiry study developing a deeper understanding of the persistent space between actual and desired use of leisure time. We explore the potential of the capability approach to aid understanding of learning disabled people’s constrained choices of leisure activities, and constrained roles as researchers, as matters of human rights and social justice.

Points of interest

- This article presents a study of how adults with learning disabilities actually spend their leisure time and how they would like to spend this time.
- A project group included people with learning disabilities, practitioners, managers and academic researchers. Learning disabled members were involved in all stages of the research.
- To make sure we could learn about the experiences of people with different abilities and impairments we used several different methods to collect information.
- Despite policies to support people with learning disabilities to develop confidence in exercising choice and achieving greater independence, we found little evidence of positive risk taking in practice.

- We argue that limiting the choices of people with learning disabilities, whether in the choice of leisure activities or whether to be actively involved in research, can be seen as a form of social injustice that prevents enjoyment of their human rights.

Keywords: learning disability, leisure time, co-inquiry, positive risk taking, capability approach.

Introduction

The significance of meaningful community participation is acknowledged in policies to enable people with learning disabilities to have greater choice and control over their own lives. Active participation in leisure activities is associated with improved quality of life and well-being, establishing friendships with peers, and providing valuable entertainment (Copestake et al. 2014). However, people with learning disabilities continue to experience loneliness, boredom and anxiety associated with unstructured free time and insufficient knowledge and skills to take control over their own social and leisure participation (Duvdevany and Arar 2004; McConkey 2011). Article 30 of the Convention on the Rights of Persons with Disabilities (UNCRPD) (UN 2006) articulates the rights of disabled people to participation in cultural life, recreation, leisure and sport on an equal basis with others. An obligation of states parties to the Convention is to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, for their own benefit, and for the enrichment of society. However, the Joint Committee on Human Rights (2008), Valuing People Now (DH 2009) and Mansell (2010) all identify barriers to the achievement of these rights in the UK raising concern about the slow pace of change.

We begin by reviewing the literature on entitlements to, and use of, leisure time by people with learning disabilities. We then share experiences of a co-inquiry study designed to illuminate gaps between actual and desired use of leisure time. We explore theoretical thinking about the barriers faced by learning disabled people in exercising choice of leisure activities. And we draw on the same line of theoretical argument to conceptualize the involvement of learning disabled people as active researchers as matters of human rights and social justice.

The Literature

Studies of adults and young people with learning disabilities in the global north suggest low levels of engagement in leisure activities requiring a high degree of personal autonomy (Badia et al. 2013), a pattern of solitary, passive, leisure activities among residents of care homes (Beadle-Brown, Hutchinson and Mansell. 2008), and the dominance of parental and professional influence in decision making about choices of leisure activities (Raghavan and Pawson 2009). Despite evidence of the potential benefits of the internet as a leisure activity including self-expression, advocacy, and the development of friendship networks, Chadwick, Wesson and Fulwood's (2013) review of published studies found that the majority of people with learning disabilities had less access to the internet than others, and not all those with access to the internet actually used it. Barriers ranged from financial, to the exclusion of people with learning disabilities from computer design to ensure cognitive accessibility, lack of regulation and poor compliance with policies of universal design, lack of training opportunities and support – including perceptions of the internet as posing risks - and challenges associated with individual impairments.

Zijlstra and Vlaskamp (2005) in the Netherlands, Emerson and Hatton (2008) in the UK, and Darcy and Dowse (2013) in Australia have reported an association between the severity of disability and participation in leisure activities. And Canadian research (Abells, Burbidge and Minnes 2008) suggests that motor problems, sensory deficits, and communication difficulties are related to the quantity, variety, and quality of leisure activities. By contrast, studies with children in the USA (Braun, Yeargin-Allsopp and Lollar 2006) and with young people and adults in Spain (Badia et al. 2011) have shown that type of disability does not have to impede participation in diverse types of leisure activity.

Research exploring preferences for leisure activities among people with learning disabilities, including those with severe disabilities and communication difficulties (Abbott and McConkey 2006; Kreiner and Flexer 2009), suggests that aspirations for greater participation in leisure activities have remained unfulfilled. A literature review by Dowling et al. (2012) concluded that lack of transport, supporters, and financial constraints constituted the main barriers to involvement in leisure activities. Buttimer and Tierney's (2005) study of students attending a special school in Ireland found that inaccessibility of leisure facilities

limited the use of leisure time to solitary, passive activities. And Raghavan and Pawson's (2009) study of young people from South Asian backgrounds also found that lack of information, individual support, and limited friendship networks restricted the young people's choices about the use leisure facilities.

This evidence prompts questions about the participation by people with learning disabilities in mainstream leisure activities (Verdonschot et al. 2009). Twenty years ago, Fullager and Owler (1998, 442-3) argued that for people understood to have mild intellectual disabilities, recreation and leisure services were 'unwittingly implicated in perpetrating stories of selfhood premised on lack', with leisure perceived as a way of occupying time, and leisure spaces as sites to manage people rather than to enable and encourage the development of identity. The sense of safety associated with such spaces, and their role in facilitating social contact have led to resistance by service providers and service users to extend the boundaries of leisure as opportunities for growth and development (Morgan 2004). Routinized and repetitive leisure activities have reinforced fixed identities and suppressed individuals' abilities to think about themselves creatively. Fullager and Owler also argued that for people with learning disabilities to develop their sense of identity, and control over new leisure activities, requires supporters to encourage self-confidence through small risk taking steps, now referred to as positive risk taking (Morgan 2004; Robertson and Collinson 2011; Seale 2014).

The development of rights-based disability discourses has been paralleled by the development of cost-saving policies of personalisation, promoted through the judicious use of words such as independence, choice and control (DH 2005). But this has also been referred to as the privatisation of risk (Ferguson 2007) and predictable concerns about risks associated with personalisation have been incorporated into the policy landscape, for example in best practice guidance on supported decision making (DH 2007). Recognizing the disabling effects of restrictive choices, policy thinking has shifted to acknowledge the (mis)use of 'risk' as justification to limit freedom and argued for the adoption of more enlightened, positive risk taking approaches (DH 2010). Yet there is little evidence of changing social practices to extend the freedoms of people with learning disabilities. Lack of staff resources combined with reluctance to expose people with learning disabilities to

risks associated with what is widely perceived as a world hostile to disabled people (EHRC 2011) have contributed to the continuing restriction of real choices by adults with learning disabilities.

Robertson and Collinson's (2011) study of community outreach teams in an English city revealed uncertainty and fear of misjudgement among staff, in the knowledge that service responses tend to be 'shaped by rare, adverse incidents rather than by everyday risks faced by most service users' (5). They called for coherent organisational approaches that support staff to avoid conservative practices that promote coercion and disrupt therapeutic relationships. The irony is that avoidance of particular risks through conservative practices increases the risk of failure to promote development and resilience (Seale, Nind and Simmons 2013). This was clearly evident in a review of international studies on the use of technologies by adolescents and adults with learning disabilities (Seale 2014) that identified the continuing exertion of power and control by supporters to limit access to transformative technologies. And Hollomotz' (2012) examination of 'choice' as a policy goal for adults with learning disabilities identified choices restricted largely to the mundane, for example, between bowling and watching television, neither of which met the goals and aspirations of the individuals concerned. A similar picture is evident in Lövgren and Bertilsdotter-Rosqvist's (2015) research in Sweden on the ways in which 'work', gender and age intersect with leisure to constrain the free time of disabled men and women.. A general lack of resources and a lack of power to claim their legal rights left them with 'too much time with too little to do' (263).

The theme of acknowledging the rights of learning disabled people was reinforced in a government consultation: 'No voice unheard, no right ignored' (DH 2015). Yet a briefing paper 'Learning Disability - overview of policy and services' (Parkin 2016), contains no mention of the views or experiences of people with learning disabilities in relation to the use of leisure time. A number of connected themes in the literature provide further clues about the current state of knowledge and understanding of the experiences of learning disabled people in accessing and participating in leisure activities. The impact of austerity on services for disabled people (Hamilton et al. 2017; Goodley, Lawthom and Runswick-Cole 2014), continuing negative public attitudes that stigmatize physically and learning disabled

people (Staniland 2010; Scior and Werner 2016), and harassment that inhibits the participation of people with learning disabilities in community life (EHRC 2011), help to explain the tension between policy and practice. Themes of social inclusion and belonging have been explored in different ways but until recently have rarely allowed us to access the experiences of people with learning disabilities in their own words (Abbot and McConkey 2006) or through alternative forms of expression.

This raises important questions about how knowledge is produced, which knowledges and whose knowledges are considered valid (Beresford 2007, Beresford and Boxall 2013). Intellectual argument about the value of lived experience in research (Van Manen 2016) supports the use of a range of different approaches to research including visual and arts-based methods to develop better understanding of people's lives and experiences, including those of people with learning disabilities, who have historically been systematically excluded from meaningful participation in research (Charnley and Hwang 2010; Hall 2004, 2010). Jongeward (2009, 233), referring to the transformative use of photography as a form of data collection, vividly articulates the use of arts-based methods to: 'bypass language barriers and thus open up a range of possibilities, including work with participants who have difficulty communicating through language due to age or disability.' Here, we argue, we must pay attention to the exclusionary practices of researchers and research funders (Walmsley and Johnson 2003; Iacono 2006; Nind 2011). As Milner and Kelly (2009, 60) explain: 'the assumption that the path to social inclusion is unidirectional, involving people with disabilities making a journey to mainstream contexts without any expectation that non-disabled people need to make the return journey, should be challenged.' Ollerton and Horsfall (2013) argue the importance of using the UNCRPD to develop and promote 'inclusive participatory action research' in which people with learning disabilities are included as co-researchers, participating in planning and conducting research that challenges power structures that have governed the production of knowledge, privileging professional expertise over experiential knowledge.

Fulfilling Lives: a Co-Inquiry Study

In this section we present a co-inquiry study (Heron and Reason 2006) to develop a more nuanced understanding of the factors influencing the use of leisure time by adults with

learning disabilities in the evenings and at weekends. The study was prompted by the concerns of a Learning Disability Partnership Board seeking the support of academic researchers to understand the poor match between provision and use of leisure services. The study was funded by Beacon Northeast, a partnership between Durham and Newcastle universities committed to supporting public engagement through co-inquiry with community-based partners (Banks and Armstrong 2014). Co-inquiry is a form of participative research 'with' rather than 'on' people (Heron and Reason 2006), based on the belief that, through membership of an enabling group, people can choose to tackle sources of distress associated with restrictive social practices (Reason 1994). It involves participants as subjects, as well as co-researchers in all stages of the research process.

A project group including members of a learning disability self-advocacy organisation and their supporters, together with practitioners, service managers and academic researchers, discussed how best to investigate the mismatch between provision and use of leisure facilities. Early discussions focussed on how we would work together before moving on to specify research questions, to design and conduct the study, and disseminate the findings (Ward and Simons, 1998) with a view to maximizing the possibility of the research achieving change. There was open discussion of the tension between the desire for 'quick answers' and argument that more profound understandings of the use of leisure time would be generated by involving people with learning disabilities in all stages of the research, with appropriate support when needed. This acknowledged that people with learning disabilities themselves were the 'owners of the knowledge' we were seeking and the people able to 'define the reality' (Reason 1994) of their use, and desired use, of leisure time. This approach also nurtured the use of existing and emerging skills among group members (Charnley and Hwang 2010). The initial phase of developing an agreed value-base was crucial in underpinning the progress of the project enabling all parties to be mindful of an appropriate working pace, focussing attention on choices of methods to maximise the participation of diverse adults with learning disabilities in contributing their views and experiences about the use of leisure time, helping to develop the confidence of disabled and 'non-disabled' researchers alike, and placing learning disabled people as producers of knowledge. These considerations were central in reflecting on the ethical aspects of the

research and in preparing the application for ethical approval, granted by Durham University Ethics Committee.

Ethical considerations

As well as addressing standard considerations of research ethics approval processes: ensuring informed consent to participation, measures to avoid harm, anticipation of risks and measures to minimize their effects, we paid explicit attention to power relations (Barton, 2005). This allowed us to guard against the marginalization of disabled researchers and participants that can easily result from pressures to complete research within a limited time period. Our approach was informed by rights-based thinking so that limiting the involvement of disabled people in the research would be constituted as unethical. We were mindful of the ‘conservative’ behaviour of some ethics committees (Iacono 2006), whose members may have limited understanding of the value of participatory forms of research, little awareness or understanding of disabled people’s rights to participate in research, and whose focus on protecting ‘vulnerable’ people may take the form of paternalistic protectionism (Ollerton and Horsfall 2013). Careful consideration of ethical issues proved effective in providing a clear set of parameters from which a wide range of adults with learning disabilities were afforded an opportunity to share their experiences of the use of leisure time and to express their views in ways they enjoyed (Boxall and Ralph 2010).

Specifying research questions

A significant ‘step’ in the research process was the specification of three research questions to address the broader aim of the research to understand why there was poor uptake of leisure services provided by the local authority: i) what do people with learning disabilities do in the evenings and at weekends? ii) what would they like to do? iii) what stops them from doing the things they want to do?

Research design

The research was designed to achieve breadth and depth of understanding and involved a two stage design. The first stage involved an ‘activity day’ attended by a large and diverse group of adults with learning disabilities to offer a broad picture of the use of leisure time. The second stage involved more detailed exploration over a longer period with a smaller,

yet still diverse, group. The two sections that follow describe the participants, the methods employed and the findings from each stage of the study.

Activity day

Held in a leisure centre the activity day was widely publicized across residential, day centre and broader community locations where poster invitations were likely to be noticed by people with learning disabilities, their families and supporters. The purpose of the day, the range of activities, arrangements for keeping safe and for giving informed consent were explained in accessible formats and/or by trusted supporters. In this way, we attracted a purposive sample (Bryman 2015) of 115 men and women of different ages and with a wide range of conditions and needs-related characteristics including speech and language difficulties. The participation of individuals with different abilities and needs was important to ensure we did not exclude understandings of the use and desired use of leisure time by those with more complex needs. Person centred planners facilitated different group activities (Coulson 2007) including a traffic light exercise to indicate the popularity of different leisure pursuits, exercises to show preferences for home and community-based activities enriched by reference to different weather conditions, and a 'dream day' exercise to reveal aspirations for the use of leisure time. Alternative activities were facilitated in a quiet room for those who did not feel comfortable in larger group settings. Familiar speech and language therapists supported participants experiencing challenges in communication to avoid what Concannon (2005 164) has described as failure to acknowledge real problems in communication when involving people with learning disabilities in service planning. There was also a facility for individuals to write or draw 'personal profiles' or to record a video diary of how they used their leisure time.

The activity day revealed a predominant pattern of passive leisure activities such as watching TV or listening to music, mostly at home, with very little engagement in activities that were creative or involved responsibility for nurturing such as caring for pets or plants. Activities outside the home were dominated by outings arranged by support staff or family members. Only a small minority was involved with sports or physical exercise and an even smaller minority benefitted from outings to the cinema, theatre, or a night club. We must of course exercise caution in equating a lack of involvement in leisure activities, whether

exclusive or inclusive, in segregated or mainstream settings, with a lack of opportunity, since diverse individuals have diverse interests and preferred activities in the evenings and at weekends. As Kiuppis (2018) reminds us, non-participation does not equal social exclusion, which occurs when people want to participate but cannot. However, findings from the activity day revealed a pattern of inability to undertake desired activities because of a lack of able and willing supporters, reluctance of older parents to be involved in community-based activities, a lack of facilities or interesting activities designed to suit people of different ages, fears about health or personal safety, strained relations between residents and staff in supported living facilities, and a lack of transport or money. These constraints in accessing desired activities which are associated with improved quality of life and well-being (Copestake et al. 2014), illustrate the fragile capacity of national and local state structures to assure the human rights of people with disabilities, specifically the right to participation in cultural life, recreation, leisure and sport on an equal basis with others (Aitchinson 2009). They also illustrate the ways in which individuals with learning disabilities lack the freedom to live their lives in ways they have reason to value (Sen 1999).

In-depth study

The second part of the study involved deeper exploration of the use of leisure time with ten people recruited from those attending the activity day. Purposive sampling was used to ensure diversity in terms of gender, age, ability and living situation (see Table 1). Drawing on evidence of the effective use of visual methods in participatory research with people with learning disabilities (Aldridge 2007; Charnley and Hwang 2010), the possibility of using visual methods was discussed with participants. They all expressed excitement at the idea of taking photographs over a one week period to show how they used their time in the evenings and during the weekend, and then expressing the meaning of the photographs to researchers. In this way, we were able to offer opportunities for realistic involvement by participants for whom research methods relying only on speech or writing would have been less accessible.

TABLE 1 ABOUT HERE

Nine of the ten participants (referred to as P1-P10 to ensure anonymity) were helped to gain confidence in operating 'single use' cameras. The tenth participant, who lacked the dexterity to handle a camera, involved her parents, with whom she lived, in taking photographs of her preferred places and activities. The exercise generated 167 photographs representing time spent with peer groups and family members, and engagement with home and community-based activities. 'Reviewing sessions' to discuss the photographs were held within two weeks to maximise continuity and minimise problems of recall. Three participants were supported by speech and language therapists to convey the significance of their photographs. The therapists were well known to the participants and committed to supporting their involvement in the research. Eliciting the subjective meanings of photographs involved the use of open questions together with non-directive approaches that involved listening, observing and reflecting back to understand the content of, and motivation for taking, particular images. Learning disabled researchers were supported by an academic researcher to undertake this iterative process that helped to distinguish consistent from inconsistent responses or reactions and also helped in exploring avenues indicated by participants to reflect the value and meanings they attached to particular images. The reviewing sessions were audio recorded and transcribed to support further analysis.

A further stage in working with the ten participants drew on techniques from participatory community planning (Macaulay et al. 1999) and involved the use of pictures depicting a wide variety of leisure activities. Following discussion of their photographs, nine of the ten participants were able to work with the researchers, who showed them pictures of diverse leisure activities, to create 'activity maps' that distinguished i) current activities, ii) activities never attempted or no longer engaged in, and iii) activities they would like to renew or try for the first time. These sessions were audio recorded and transcribed to support understanding and interpretation of participants' decisions.

The photographs and activity maps generated a body of visual data which, aided by the transcripts of reviewing sessions and development of activity maps, were discussed, interpreted and categorized, identifying themes of place, people, type of activity, in/dependence, satisfaction (indicated by repeat photographs), choice (indicated by the

range of activities portrayed), and barriers or constraints. This part of the study underlined the dominant use of leisure time spent at home watching TV or DVDs, listening to music or radio, or reading. Routine tasks including cleaning, tidying and cooking, were a feature of evenings and weekends for all but one participant whose physical condition prevented her undertaking practical tasks. Discussion of individual photographs prompted more detailed accounts of engagement with particular activities. For example, P1 commented with pride on the photograph of her 52 inch TV screen: 'I watch soaps: Neighbours, Home and Away and Hollyoaks.' And P2 explained: 'Monday night, I am busy with cooking and Sunday as well. I have to make all for cooking.' By contrast, photographs of home-based leisure time involving physical activity or creative interests were conspicuous by their absence except for P8 who expressed great pleasure in discussing the photographs of the chickens she tended, providing her with a clear sense of caring responsibility.

Participants also generated photographs involving visits to pubs and cafes, and shopping trips, which were almost entirely organised by staff and family members. Although eight participants referred to using public transport, only three were confident enough to travel alone. Participation in group activities outside the home, predominantly organised by agencies such as Mencap or advocacy groups, offered a chance to meet with people with similar disabilities and a site to develop friendships (McConkey 2010). P5, discussing photographs of her women's group, explained:

P5: Oh ... the lady's group, at night time, Thursday, evening time. Six thirty to eight.

Interviewer: Do you have many friends there?

P5: That one, D, she is a close friend.

Interviewer: Do you often meet D here?

P5: Yes, [also] drop in [place name] and [place name] youth club....all women.

Social use of leisure time was most commonly spent with other adults with learning disabilities. Exceptions were two younger participants living with their parents who facilitated their involvement in wider family activities. Those with communication difficulties and more complex needs were able to access various activities outside the home

only if staff or family members made arrangements for them. For instance, nearly half of P7's photographs were taken on an organised visit to the park and she was animated while talking about these. P10's photographs, taken by her parents, showed a wide range of weekend activities including visits to the beach, a concert hall and a pub.

There was a contrast between participants living independently or with their families who spent leisure time with one or two other people, and participants living in supported accommodation who presented a pattern of group leisure activities with other residents and staff. Three participants living in supported accommodation were able to combine group activities with other residents during the week and family-based social activities during weekend visits. For example, P2:

Interviewer: What did you do Wednesday night?

P2: I went to Mencap club with them [who live together]

Interviewer: What do you do at the Mencap club?

P2: Play games, talking, play cards, and cup of tea ...

Interviewer: What did you do Saturday?

P2: Me sister, A is my brother-in-law. J is my sister ...

Interviewer: Where did you take this photo?

P2: In a house, J's house,

Interviewer: Did you visit your sister's house?

P2: Aye, every Saturday

Four participants aged under 40, living independently, or with supportive staff or family members, had more opportunities to engage in community-based activities. However, they exercised little autonomy, with these activities being predominantly organised by others. Involvement in sports or exercise activities such as indoor bowls or snooker/pool featured in the photographs of seven participants and were all arranged through organised social

groups or day centres. The three participants aged 60 or over portrayed themselves as watching or listening rather than playing sports.

Participants' aspirations were expressed as the desire to try new activities or to reengage with activities enjoyed in the past. Seven participants wanted to be involved in sports or physical activities and eight expressed a wish for outings involving fun such as going to a concert or theme park. Supported by speech and language therapists, two participants with communication difficulties were able to convey ideas about the activities they would like to engage in. The following extract is taken from the transcript of the picture placement exercise with P8:

Researcher: (supported by therapist using Makaton). What would you like to do?

P8 carefully looks at the pictures of activities and indicates a picture of camping.

Researcher: Would you like to go camping?

P8: Yes (and makes sounds recognized clearly by the therapist as expressing pleasure)

Further exploration revealed that P8 had been on holiday the week before taking her photographs, raising the possibility that she had seen a camp site and associated this with her wider holiday experience.

P7, who lived in a residential home indicated through her choice of pictures and expression of excitement that she would like to go to a social club. This contrasted with her lack of interest in outings organised by her day centre. Further choice of pictures showed that she derived most pleasure from social outings to the pub with fellow residents. Other participants in this part of the study conveyed clearly that staying at home was not a positive choice for them. For example, P1 stated: 'Staying at home is really boring. I would like to go out more.' And P5, when selecting pictures of activities she would like to revisit explained her choice of a picture of: 'canoeing, used to long time ago at centre, when I go camping, do it, I want to do it again.' And P9 explained 'I think I would like to try cinema, theme park, erm, that one, dancing.'

An important message here is that for leisure activities to contribute to an individual's sense of living a life she or he has reason to value (Sen 1999) they need to be tailored to reflect individual preferences rather than what can be conveniently arranged on the basis of perceived ability and/or level of independence. As Stalker (1998) has long argued, people with learning disabilities are not a homogeneous group and have a range of preferences and priorities. Identifying preferences requires time and deep engagement in order to avoid assumptions based on superficial engagement that produce what Blow (2008) has called 'one version of the truth'.

Participants disclosed three overlapping barriers in this second part of the study. First was concern about injuries, conditions or health problems that inhibited the involvement of seven participants in specific leisure activities. For example, P4 explained:

I had a bit of accident when I lived in [place]. I bought a long size of bottle of wine. I bought a big bottle of wine. I drank and I had a bit of an accident... and made a scar that put me off going to swimming.

By contrast, P9's social life was restricted by an acute hearing problem leaving her uncomfortable with loud music or noisy crowds. She preferred quiet surroundings and the majority of her photographs indicated activities at home such as reading, writing or helping her parents. These examples serve as a reminder of the importance of gaining a deeper understanding about preferences for the use of leisure time. This involves particular challenges for those working with individuals with communication difficulties where there is a high risk of misinterpreting intended meanings (Blow 2008) and reinforces the importance of communication skills development among staff and supporters.

A second barrier was the limited availability of appropriate leisure facilities. This was a particular issue for participants aged over 40 and those with more complex needs. Older participants referred to having stopped sporting activities when they left school or 'got old'. P6, aged 63, talking about a picture of basket/netball explained:

netball, it's not easy, it's hard. I now remember in school, yard, domestic ball I used to have... medicine ball, bigger ball, ball, football. I can't run, no not. Walking, walk slow. I think walking is easier doing than running.

But he went on to select pictures of sports and expressed the desire to engage with sporting activity again if he were given the chance. P10, a young woman with complex needs including communication difficulties, enjoyed swimming but her parents struggled to find a swimming pool with facilities to accommodate her.

The third barrier was related to participants' fears for their personal safety that increased reluctance to become involved in community-based leisure activities. Five participants referred directly to their fear of the dark. For example, P1 said: 'I am really nervous about dark...I don't like walk in the dark.' And P5, discussing what she had done on the Wednesday of the week during which she had taken her photographs explained: 'what I were doing on Wednesday? ... I know, not going out at night time, never go out, I don't like dark.' P2 explained his reluctance to go out following an experience of being attacked by school children in an incident now more commonly recognized as disability hate crime (Roulstone, Thomas and Balderston 2011), a phenomenon receiving high profile media coverage following the murders of two men with learning disabilities in the region (Macdonald 2015). The limiting impact of fear, whether of the dark or well-founded fear of the hostile behaviour of others (Sin et al. 2009), on both women (Whitzman 2007) and men in this study, underlines the importance of careful analysis of the bases of reluctance to engage in community-based activities and identification of strategies to remove these barriers. While disabled and non-disabled women alike, have consistently been found to be more fearful of crime than men, and more restricted in their mobility as a result (Butler and Bowlby 1997; The Daisy Project 2010; Doran and Burgess 2011), Pain (2000) has argued that understanding fear of crime is linked not only to where people live and who people are, but also to how they experience change in their local environments and how they perceive 'others'. And more recently Chakraborti and Garland (2012, 510) have argued that vulnerability and difference are more important than individual identity in determining susceptibility to hate crime, demanding an understanding of how identity intersects with aspects of the self and other situational and contextual factors.

Evidence of the effects of fear in this study might be susceptible to different strategies focusing on individual empowerment, enhancing the accessibility of the environment or influencing wider societal attitudes to disability. But importantly we argue that 'reluctance

to go out' should not simply be accepted as part of an individual's identity, rather it should be explored, understood and addressed, bearing in mind that positive engagement in community-based leisure activities is likely to require individually tailored support to enable individuals to feel safe and to avoid reinforcing earlier experiences of social exclusion.

Discussion

Findings from the activity day with 115 participants and the in-depth study with ten individuals suggest that, with few exceptions, leisure activities for adults with learning disabilities during evenings and weekends involved passive activities in the home setting or organised activities outside the home. These findings are not dissimilar to the wider picture offered by the studies reviewed earlier in this article. But through the use of co-inquiry and a range of participatory research techniques, we have been able to develop a deeper understanding of opportunities and constraints, desires and fears surrounding engagement with leisure activities.

The apparent lack of progress in facilitating individual choice of leisure activities raises important questions about the continuing gap between policy, implementation strategies such as positive risk taking (Morgan 2004), and practice. It is, of course, easy to offer explanations linked to resource constraints (Boxall, Dowson and Beresford 2009). But our study shows that priority is not being given to supporting adults with learning disabilities to discuss their individual interests and preferences. For those living in supported housing, group activities organised by staff all too easily become the norm. Barriers to engaging in community-based activities identified by participants ranged from lack of available staff and parental reluctance, to concerns about health, personal safety or lack of appropriate activities. Reflecting a culture of low expectation (Aitchison 2003) and adaptive preferences (Begon 2015), these barriers were not expressed in terms of dissatisfaction or demand for individual support by disabled participants. Rather they were associated, by practitioner and manager members of the project group, with funding cuts linked to austerity politics. However, the use of visual methods allowed us to see that disabled participants did express interest in returning to leisure activities they were no longer able to enjoy, and in trying new leisure activities.

Growing older was one explanation for curtailing participation in particular activities, underlining concerns about ageism in social care (CPA 2009). These concerns have been most clearly articulated in relation to service provision for people with learning disabilities entering the world of 'older people's services at age 65 (Jenkins and Steff 2011; Thompson 2002). But we argue that questions of ageism deserve attention in planning the use of leisure time for all adults with learning disabilities. An important challenge lies in ensuring that all adults with learning disabilities are supported to express their wishes before decisions are made about services to be provided. As Stainton (2002) has argued, the challenge is to create a way in which individuals can articulate their choices and have their realistic claims met without losing autonomy.

This brings us to the second focus of discussion, the value of involving people with learning disabilities in undertaking research about matters of importance in their lives. Debates about the value of introducing different perspectives to research have been helpfully summed up by Glasby and Beresford (2006) who argue the importance both of the lived experiences of service users and the closeness of researchers to the research topic. This co-inquiry study was conducted, at all stages, by learning disabled and 'non-disabled' researchers working together with appropriate support where necessary. We convey the value of this approach using words from the accessible report of the study:

We wanted to make sure that people with learning disabilities were involved properly in this research and so it took a long time to do [but] because we took our time we were able to make sure that lots of people with learning disabilities were involved and this means that we can believe what we found out... Nearly everyone who joined in told us they enjoyed taking part in the research. We think this shows that people with learning disabilities could be part of more research in the future.

Developing theoretical understanding

In this section, we pay attention to theoretical models and approaches that can aid our understanding of learning disabled people's experiences of leisure time and use of leisure services. Seale et al. (2015) have argued that the past thirty years have seen transformative changes in services for disabled people. The disability movement has been

responsible for shifting understanding of disability from an individual model that focuses on the potential to treat individuals with limiting conditions or impairments, to a social model that focuses on structural factors that limit opportunities for disabled people to reach their potential and claim their rights. The social model has been the subject of continuing critical debate (Oliver and Barnes 2012; Oliver 2013) with calls for more nuanced insights into the role of culture in shaping diverse understandings of disability, and for the recognition of positive disabled identities that have forged, and been forged by, self-advocacy movements (Riddell and Watson 2014).

Over the last two decades, the transformative achievements associated with the adoption of the social model have been under attack by the tightening grip of neo-liberal political ideology. The sweeping privatisation of services and the principle of individual responsibility that underpins the conveniently named policy of personalisation, have led to what Redley (2009) has referred to as 'the stalled welfare of citizens with learning disabilities'. This has been exacerbated by a decade of austerity politics following the global financial crisis of 2008 and by the slow pace of change in achieving more positive public attitudes to people with learning disabilities. In the context of this study the gap between policy rhetoric and reality, of choice, independence, control, and positive risk taking, has already widened with reductions in care packages, in facilities designed for people with learning disabilities, and the closure of many public leisure facilities such as parks and swimming pools, as experienced in this and other local authority areas (Langan and Miller 2015). Recent research by geographers suggests that the loss of collective and formal spaces of care heightens the need for citizenship and advocacy work that can facilitate opportunities to demonstrate capabilities as well as vulnerabilities through facilitating opportunities to meet friends, tackle isolation, and avoid harassment (Power and Bartlett 2018, 353-354). However, harassment and hate crime remain 'Hidden in Plain Sight' (EHRC 2011; Macdonald 2015), and broader exclusionary practices including 'misconceptions, negative attitudes and discrimination' (Scior and Werner 2016, 9) challenge the very notion of social justice for people with learning disabilities.

It is here that we turn to what must necessarily be a brief exploration of the capability approach (Sen 1999, 2005, 2011), that focuses on the capability of individuals to live the

kind of lives they have reason to value. Burchardt (2004), writing in this journal, has provided a detailed articulation of the potential of the approach to strengthen the social model of disability and the potential of the social model to demonstrate applications of the capability approach. Here we apply the principles of the capability approach to the findings of our study of the use of leisure time, to suggest a different lens through which matters of human rights and social justice for people with learning disabilities can be viewed and argued in the public domain. Underpinning contemporary measures of human development, the capability approach combines argument about human values, human rights and social justice. The approach is concerned with the well-being of individuals with diverse characteristics and resources, in diverse physical, social, economic, and political environments, resulting in unequal opportunities to lead valued lives (Mitra 2006). The approach focuses not only on available resources but also on the freedom to use resources in ways that achieve valued outcomes. In considering questions of disability and social justice, Sen (2004) has argued that disabled people not only experience inequality and disadvantage in terms of their opportunities to earn an income, but also face further disadvantage in converting any income they have into 'freedom to live well' (3) and converting 'social facilities into actually usable opportunities' (5). Commenting on the narrow thinking that underpins disability policies, he declared: 'Given what can be achieved through intelligent and humane intervention, it is amazing how inactive and smug most societies are about the prevalence of the unshared burden of disability' (8). Sen warns against complacency in the face of expressed satisfaction by disabled people arguing that their preferences may represent an adaptation to the oppressive circumstances in which they live. Their choices are constrained and they are not able to make truly informed and free choices (Begon 2015; Elster 2016).

The notion of adaptive preferences is not without controversy. Sen (2004) and Nussbaum (2009) argue that, while entitled to achieve lives free from oppression, members of many minority groups, including disabled people, often settle for what they have rather than exercising agency to resist the oppressive aspects of the environments in which they live. Others, such as Barnes (2009) argue that the concept of adaptive preferences serves to stigmatize by suggesting that disabled people are 'less than' non-disabled people, denying the sense of pride felt by those who embrace a disabled identity positively. Yet others argue

that the capability approach itself rests on an assumption that all people wish to exercise agency. Reader (2007 580) explains agency as: 'a vast invisible structure which pervades our culture. It says: when I am an agent, I am, I count. But when I am passive, incapable, constrained, dependent, I am a less person, I count less.' And she tasks her fellow philosophers with exploring what people cannot do or become, the ways they are constrained, the contingencies that structure their responses to the world and the ways they are connected to, and dependent on, other things. Trani et al.'s (2011) discussion of the implications of the capability approach for public policies concludes that it offers a way of overcoming the limits and contrasting evidence arising from the use of models of disability. However, Trani and colleagues stress that using the capability approach for policy planning requires an understanding of the values expressed by those for whom the policy is to be formulated, and information about individual agency.

Conclusion

Our study offers a rather pessimistic picture of the effectiveness of government policies in enabling adults with learning difficulties to lead fulfilling lives. Twenty five years after the implementation of the National Health Service and Community Care Act, the principle of tailoring services to individual need continues to be compromised by shortfalls in funding and by the capacity of the social care workforce to practise in less risk averse, more imaginative, ways using available resources to support adults with learning disabilities to exercise the same choices as anyone else. More optimistically our study shows that it is possible to push boundaries, and to open up what Seale et al. (2015) refer to as new, contested or messy spaces to develop participatory approaches to research with learning disabled people, in this case through the use of co-inquiry. Viewing our experiences and findings through the lens of the capability approach, we present clear evidence of agency as participants responded with enthusiasm to invitations to communicate their experiences, preferences and aspirations for the use of leisure time. But we were also able to respond to Reader's (2007) call to acknowledge 'the other side of agency' as participants showed how they were constrained in their choice of activities and how, for the most part, they were dependent on others to engage in leisure activities outside their own homes. Importantly we argue that the capability approach, notwithstanding its limitations, has the potential to shine a light on questions of social in/justice for people with learning

disabilities in terms of their freedoms or 'unfreedoms' (Sen 1999) to lead lives they have reason to value.

Developing recommendations from this study, we start by quoting from the accessible summary report:

The council and other people who help and support people with learning disabilities will have to think about how they use person centred planning and direct payments and personal budgets. They will also have to think about how to help support staff to use 'positive risk taking' in their work ... to make sure that all people with learning disabilities are given the chance to lead a good life.

Despite the strengths and achievements of the study that has included participants with diverse abilities and needs, we acknowledge that there are further aspects of the use of leisure time that we have been unable to explore in any depth. Future research could helpfully focus on developing more nuanced understandings of the lived experiences of leisure among learning disabled women and men of different ages, ethnicities, sexual orientation, parental and employment status, and other characteristics that influence experiences of oppression or relative freedom. And there remains a clear space to develop current understandings of the complex relationships between actual and desired leisure activities, social networks that might enable, or be enabled by, engagement in leisure activities, and the desires and capacities of people with learning disabilities to exercise agency or patiency (Reader 2007). But we must also develop understanding of the capacity of the state, of advocacy and self-advocacy organisations, local communities and families to honour the rights of disabled people (UNCRPD 2006) to participation in cultural life, recreation, leisure and sport on an equal basis with others, having the opportunity to develop and utilize their creative, artistic and intellectual potential for their own benefit, and for the enrichment of society.

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